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ABSTRACT

This paper discusses resources needed by infants and toddlers who are disabled and by their families, with respect to policy implementation of Part H of the Individuals with Disabilities Education Act. The paper emerged from a series of focus group discussions with health professionals in five states. Out of the open-ended discussions emerged several themes, including: medical requirements of the children in addition to treatment of developmental delays; identification of professional human resources; programmatic resources for treatment and evaluation; and structural resources such as insurance coverage and transportation. Policy strategies are suggested in the areas of resource distribution, multidisciplinary cooperation and communication, and financial support. (7 references) (JDD)

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SHORT REPORT

February, 1992

Carolina Policy Studies Program

PROVISION OF SERVICES TO HANDICAPPED INFANTS AND TODDLERS WITH DEVELOPMENTAL DELAY: THE HEALTH PERSPECTIVE ON RESOURCES

Patricia Fullagar, Conleth Crotser, James Gallagher, Frank Loda, and Theresa Shieh

Introduction

The following paper on the issue of resources that are needed both by infants and toddlers who are disabled and by their families emerged from an exploratory study conducted by the Carolina Policy Studies Program (CPSP) on the implementation of Part H of IDEA (formerly P.L. 99-457).

The Carolina Policy Studies Program held a series of focus group discussions with health professionals in five states. The states (Colorado, Hawaii, Maryland, North Carolina, Ohio) were selected for their geographic and cultural diversity and leadership shown by policy makers and service providers in meeting both the needs of children with disabilities and the needs of their families. Health professionals were nominated in each of the states through recommendations of professionals and parents who were involved in programs for young children with handicaps. Those who were recommended were invited to participate by CPSP staff in focus group sessions. The meetings were open-ended, and CPSP staff encouraged the presentation of all significant issues related to provision of services. A court reporter recorded and transcribed each discussion.

Out of these open-ended discussions emerged several themes that seemed to have direct bearing on policy implementation in the states. The topics on which the discussions focused transcended state and regional boundaries and were national in scope. Each of these themes is presented in a brief report.

Background

Community-based care is a primary objective of Part H of IDEA. Community-based services increase the potential for equity of access by all who are in need of specialized care (Schorr, 1986) and continue the trend toward decentralized care (Hutchins & McPherson, 1991). Yet, as Hutchins and McPherson (1991) noted, necessary resources that include social services (e.g., housing, nutrition, home-based and center-based programs), in addition to health and mental health care, are not readily available at the community level.

The community-based, direct service, health-care providers with whom we met devoted more time to the description of difficulties with availability and accessibility of resources than to any other topic. This report shares a summary and synthesis of their descriptions.

Findings

Many of the infants and toddlers who are identified as having developmental delays have significant medical requirements, as well. Some of these very young infants and children will be, in fact, characterized as medically fragile, and may

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present concerns of basic survival.[1] Consequently, these children and their families require complex services and highly trained support personnel who can provide comprehensive, coordinated, multidisciplinary services.

The health care providers whom we interviewed conveyed a clear and distinct message. Many children who are being served today by human service providers, including health care providers, require long-term care, and that care must include attention to the overall development of the child. Long-term care, as described by the physicians and nurses who participated in our discussion groups, involved the development of a positive, working relationship with a child's family. Moreover, long-term care of children who are developmentally delayed likely will comprise supplemental services, such as special education, assistance with transportation, attention to other family members and issues or concerns, as well as help with finances. Issues of availability and competency of service providers; programmatic availability, quality, and accessibility; and accommodation by various societal structures to diverse human needs were broad themes that emerged from these discussions.

Human resources. During periods of time that infants or young children with developmental delays are medically fragile and require acute medical attention, professional resources are available in a tertiary-care center:

> It's a university-affiliated program ... that [is] a major provider of services ... dedicated toward severe multiply handicapped. (Developmental pediatrician in a university hospital)

Health care providers expressed confidence about the quality of medical care provided in these centers. It is important to note, however, that these same providers expressed considerable concern for the overall development of the child and for the development of a relationship between the family and the child. The concern for overall development included the desire to see the child enter the home and community-based setting as quickly as possible.

The discharge from a tertiary-care facility often was delayed, however, by the lack of available community-based care for the child:

> ... we expect that child to go home ... three counties away ... in a very rural area. A child who needs not only nursing care ... because of having a tracheotomy ... and an endotracheal tube that needs suctioning ... but comprehensive care with physical therapy, speech therapy. (Pediatrician in private practice)

The solution to the problem of locating competent and appropriate community-based medical services most often seemed to be a function of an informal network among professionals:

> The ... tertiary care nurseries will not discharge a baby without having identified a care provider back in the home town: and we're asked often.... Most of us have the benefit of training in-state.... It's easy to pick up the phone and informally ask. (Pediatrician in private practice)

Only occasionally was a systemic approach mentioned, and it was often a community-based system rather than a more comprehensive one such as a system that included a region or a state:

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[1] It is estimated that nearly all infants in the group, birth-to-three months, who can be identified as developmentally delayed, also will be considered to have significant medical complications and, perhaps, to be medically unstable or fragile. If the entire Part H population is considered (children, birth-to-three years, who are developmentally delayed), then the percentage likely is quite small. Present statistics on this population do not permit a fine-grained estimate.

> We've had a number of physicians that have helped us in a speciality area of referrals. The communications start becoming more continuous, more reporting. Of course, the Health Department has always been very, very helpful. (Pediatrician in private practice)

The issue of finding specialized medical care that was community-based seemed to be broadly-based and a far reaching one, which affected medically fragile children as well as those who were medically stable. Either specialists were not available in many communities or their training was not appropriate to the particular needs of infants and toddlers:

> There are only a certain few of those super specialists ... who we trust. ... I don't trust my local urologist with a developmentally handicapped child. I don't trust the orthopedist not to do something that was in vogue thirty years ago. (Pediatrician in private practice)

There are, in fact, only a relatively small number of medical specialists trained in the care of these children, and, these practitioners are concentrated in teaching hospitals and tertiary care facilities. In some instances, specialized medical teams traveled to local communities:

> ...the team [neonatologist, orthopedist, etc.] comes out to the community hospitals on a regular basis -- quarterly, I guess. And you have an opportunity to discuss issues ... with the neonatologist who you've spoken to on the phone. (Pediatrician in private practice)

Outreach consultation by medical specialists to community-based physicians did not seem to be widespread, however.

In addition, these professionals spoke of the difficulty in locating non-health care providers with expertise in necessary areas:

> We've formed a consortium of five counties trying to pool resources. But, not only is there not money to hire more people to process those children and get them into the system, we also don't have the PT's and OT's to prove the service once you identify them. (Pediatrician in private practice)

They discussed the turn-over among such personnel

> Children's services do not pay as well as many adult-oriented services, particularly physical therapy. And so it's hard to attract people to some of our needs. (Developmental pediatrician in a clinic with a focus on developmental disabilities)

and the concomitant difficulty in evaluating the need for specialized services and quality of care provided in allied health and non-medical areas:

> What are the resources in my area and where does this child need to go and then how do I help make decisions? There aren't a whole lot of pediatricians and family practitioners who know a whole lot about whether this child needs speech therapy or occupational therapy. (Pediatrician in a rural public and migrant health department)

> I also have a hard time as a pediatrician wondering how much does this [child] need. ... I'm not sure how much physical therapy a child really needs. I don't know.

(Neonatologist in a community hospital)

Working relationships between health care and non-medical care providers were described as facilitated through informal networks that were formed over time. A major problem expressed by the health community was the transient nature of non-health and allied health positions. The perception often expressed appeared two-pronged. That is, except for medical services, financing for human services (e.g., specialists in early intervention, speech, physical, and occupational therapy, social work) is not consistent and the positions disappear at times. In addition, there is a high frequency of turnover among individuals filling these positions. In fact, the discussions suggested that these problems may be two facets of a single issue that is directly related to financing and indirectly related to lower professional status.

Concern was expressed repeatedly in the focus groups for the overall development of the child, the family, and the relationship between the child and the family. Knowing where to refer families and how to evaluate the quality of non-medical professionals, in addition to the overall availability of these professionals, were topics addressed in the discussions.

Programmatic resources. Children with developmental disabilities require complex programs for treatment and evaluation, as well as highly skilled professionals to staff those programs. Many of these children require multiple types of services, and comprehensive approaches that encompass physical, emotional, developmental, and family needs. Although such programs were available in many areas, they were not universally available. Moreover, issues of affordability and accessibility were frequently raised.

The health care providers spoke of the need for community-based programs that offered a wide array of services, and alternative models for providing care:

> Let's look at another model, the model of the public school system ... [where] more and more services [are] provided: hearing screening, vision screening, flossing and rinse programs .... Each child is entered into a day-care system ... you can bring services into that setting. (Pediatrician in private practice)

Many families wish home-based treatment programs for their infant, whereas others will want center-based programs. And, although center-based programs can provide families with much needed relief from the constant demands of care and can facilitate parental involvement with the other demands of daily living (e.g., other family members, employment, recreation and relaxation), there exists the potential for reduced parental decision-making and involvement with their child who is disabled or delayed:

> That creates the same problem of services provided in the school, and that is that you erode the family's involvement in decision-making and setting priorities. It may be inevitable, but I see that as a risk. (Pediatrician in a private, not-for-profit, child advocacy group)

The need for programs that could provide respite care was also frequently voiced by these health care providers:

> The provision of respite is one of the issues. Families become house bound for two years after a high risk preemie come home from the NICU [Neonatal Intensive Care Unit]. (Nurse in a community hospital)

> If there's a good supporting cast in [home-based care for a child with developmental delays] it may work. But with time that begins to wear thin, and the depression and the anxiety and the stress on the families is unbearable. (Family practice physician in private practice)

Even when programs were available, there often were waiting periods of six months to a year. This suggested that levels of funding and/or levels of staff availability were not adequate to meet the demand for service:

> I think the most significant barrier ... is the waiting period. It's tough to convince a lot of parents that there is something wrong. If you get the parent believing how important it is to get there and then you tell them, "wait six months," that just doesn't work. (Pediatrician in private practice)

Structural resources. In addition to needing human and programmatic resources, the families of infants and toddlers with developmental disabilities are in need of accommodation from a variety of societal structures. The health care providers who were involved in this study specifically raised issues associated with insurance coverage and transportation.

Medical insurance companies, including Medicaid, place restrictions on the care that can be provided to these families and their children. For instance, limitations can be placed on parental presence and attention to their seriously ill child. Moreover, reduced parental presence can result in parents being asked to sign blanket permission for medical procedures, thus reducing parental involvement in and control over critical decisions:

> ... the deal we struck with this mother who couldn't stay in the hospital any longer because Medicaid wouldn't allow her was that she would go home having given us permission to do the [blood] exchange transfer in the middle of the night and we would send the cops if anything went wrong. (Pediatrician in a community hospital)

Many problems that result in delayed development are not covered by medical insurance, or there is a considerable lack of consistency in what is covered among insurance companies, including Medicaid:

> ....let's say a child has some delayed speech. ... If I can say that [the] delay is due to ... some medical indication then they will consider giving some limited help but a large number of problems that need help aren't covered by insurance. (Pediatrician in private practice)

Of critical importance is the inability to receive reimbursement for non-medical services. This includes efforts of professionals to assist the family with coordination of care:

> It's my strong contention that child health associates and pediatric nurse practitioners and social workers, pediatric social workers are in a better position (than pediatricians) to do a lot of this other stuff (service coordination) ... [but] they're not reimbursable. (Pediatrician in private practice)

Transportation emerged from the focus discussions as a major concern, as well. It can have a significant impact on the care received by the child and the family. Many services needed by young children with developmental delays are available only in urban areas or associated with tertiary care centers. Not all families have dependable or readily accessible transportation:

> ... all over [our state] transportation is a terrible problem. Either you live ... where nothing is closer than 20-some miles, ... I mean driving 40, 50 miles ... is nothing ... or you live in a city that has seriously marginal public transportation service. (Pediatrician in a community hospital)

> [It] takes an hour and a half on a good day and three bus transfers to come in and see your preemie baby: therefore [the mother] doesn't come in. (Pediatrician in a community hospital)

Such factors have an impact on the accessibility of care, as well as on the quality of the care that is provided.

Summary and Discussion

Infants and toddlers with developmental delays and their families are in need of a wide array of resources, which can include the use of sophisticated medical technology and procedures over a long period of time. Concomitantly, these infants and young children are developing intellectually and socially. They and their families, moreover, are in the earliest stages of developing an interactive parent-child relationship. Resources that are diverse and provided in a flexible manner in order to accommodate the many needs of families are in great demand, but presently are in short supply. Resources are needed at the community level in order to maximize the development of children and families in the most normal way possible. However, the distribution of resources presently is highly uneven, which contributes to a considerable inequality of access to services for many children and families.

The physicians and nurses who contributed their experiences and ideas to this exploratory study spoke at length on the shortages and uneven distribution of appropriately trained personnel who were needed to provide health and other human services. An earlier study conducted through the auspices of the Carolina Policy Studies Program (Yoder, Coleman, and Gallagher, 1990) documented severe shortages of personnel among the allied health fields of physical and occupational therapy and speech pathology. In fact, as Yoder and his colleagues discussed the present personnel shortages, they described a scene that is rapidly growing more critical as the demand for highly skilled personnel outstrips the supply. Personnel in health, allied health, education, and social services are need by our nation's youngest citizens and families attempting to care for these most vulnerable children are in dire need for increased support.

The health care providers with whom CPSP met to gather the information for this report cited numerous difficulties with insurance regulations and reimbursement procedures. These problems have been previously documented (e.g., Clifford, Kates, Black, Eckland, & Bernier, 1991). Clifford and his colleagues noted that administrative personnel must remain constantly vigilant in order to keep up with changes in the regulations issued by private insurance companies and by Medicaid. These researchers also observed that "It is not unusual for personnel to spend a year or more working on access to a single source" (Clifford et al., p. 2).

The problems associated with insurers are only part of the overall issue of financial support for services that are called for by Part H of IDEA. States are experiencing severe difficulties in providing the financial resources that support human service programs and personnel (Clifford, 1991; Clifford et al; Kates, 1991).

Implications and Suggested Strategies

Resource distribution. The findings in this report are in concert with the generally recognized problems related to the distribution of highly trained medical as well as non-medical human service providers. Some states attempt to address this issue by sending teams of medical and allied health personnel out from tertiary-care or teaching hospitals to remote or rural sections. These teams rotate among specific locales on a regular basis, resulting in times when highly skilled professional care is not readily accessible to families. In addition, there is rotation among the individuals who form the teams. Families and their children may receive care from highly skilled knowledgeable professionals, but the care often is provided by an array of individuals who are filling a professional role. This lack of continuity leads to disruption in the building of a strong relationship between professionals and families.

Multidisciplinary cooperation and communication. When health-care providers reported that they have difficulty determining the type and quality of non-

medical intervention that is needed by children and families, issues related to training of professionals and communication among professionals may be implied. For instance, a recent report (Pearl, Brown, & Myers, 1990) on a model system that was developed to provide transition from a neonatal intensive care unit (NICU) to community-based care called for increased communication among care providers. Pearl and her associates found that teams of professionals whose expertise encompassed both medical and developmental needs assured successful multidisciplinary communication. This facilitated mutual respect for problem-solving and communication. Participation as active members of multidisciplinary teams by students in health-care education (medical and nursing students) and by post-graduates (residents) could serve to expand their awareness of the contributions of other types of professionals. Of course, it is equally essential that those in allied-health and other non-medical (e.g., education, social work) programs receive similar experiences.

Financial support. Without adequate financial support, shortages in personnel and programs that respond to the challenges of Part H of IDEA will continue. Clifford and his colleagues (1991) recommended that Medicaid coverage be available for all Part H services, regardless of family income. This means that as each state implements Medicaid, it should elect to provide coverage for non-medical services, such as service coordination or educational intervention, as well as for medical care, as several states have done. In addition, coverage for transportation should be universally extended. Personnel and programs likely will continue to be concentrated in locations with a high population density. Therefore, many families will continue to experience a decreased level of access to necessary services. Coverage for transportation costs incurred in gaining access would ameliorate, although not solve the problems associated with transportation and the unequal distribution of personnel and programmatic resources.

Additional financial resources, which could be made available by allocating a portion of all federal funds affecting children for Part H services (Clifford et al., 1990), including private and public insurance, are crucial to the implementation of Part H of IDEA. It is essential that all other resources, personnel and programmatic, rest on a firm financial base.

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